

113TH CONGRESS
1ST SESSION

S. RES. 310

Designating December 3, 2013, as “National Phenylketonuria Awareness Day”.

IN THE SENATE OF THE UNITED STATES

NOVEMBER 21, 2013

Mr. ISAKSON (for himself and Ms. BALDWIN) submitted the following resolution; which was referred to the Committee on the Judiciary

RESOLUTION

Designating December 3, 2013, as “National Phenylketonuria Awareness Day”.

Whereas phenylketonuria is a rare, inherited metabolic disorder that is characterized by the inability of the body to process the essential amino acid phenylalanine and causes mental retardation and other neurological problems, such as memory loss and mood disorders, when treatment is not started within the first few weeks of life;

Whereas newborn screening for phenylketonuria was initiated in the United States in 1963 and recommended for inclusion in State newborn screening programs under the Newborn Screening Saves Lives Act of 2007 (Public Law 110–204; 122 Stat. 705);

Whereas approximately 1 out of every 15,000 infants in the United States is born with phenylketonuria;

Whereas the Phenylketonuria Scientific Review Conference in 2012 affirmed the recommendation of lifelong dietary treatment for phenylketonuria made by the National Institutes of Health Consensus Development Conference Statement 2000;

Whereas women with phenylketonuria must maintain strict metabolic control before and during pregnancy to prevent fetal damage;

Whereas a child born from an untreated mother with phenylketonuria may have a condition known as “maternal phenylketonuria syndrome”, which can cause a small brain, an intellectual disability, birth defects of the heart, and a low birth weight;

Whereas phenylketonuria is treated with medical food;

Whereas although there is no cure for phenylketonuria, treatment involving medical food and restricting phenylalanine intake can prevent progressive, irreversible brain damage;

Whereas maintaining a strict medical diet for phenylketonuria can be difficult to achieve, and poor metabolic control can result in a significant decline in mental and behavioral performance;

Whereas access to health insurance coverage for medical food varies across the United States;

Whereas the long-term costs associated with caring for untreated children and adults exceed the cost of providing medical food treatment;

Whereas scientists and researchers are hopeful that breakthroughs in phenylketonuria research will be forthcoming;

Whereas researchers across the United States are conducting important research projects involving phenylketonuria; and

Whereas the Senate is an institution that can raise awareness of phenylketonuria among the general public and the medical community: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates December 3, 2013, as “National
3 Phenylketonuria Awareness Day”;

4 (2) encourages all people in the United States
5 to become more informed about phenylketonuria;
6 and

7 (3) respectfully requests that the Secretary of
8 the Senate transmit a copy of this resolution to the
9 National PKU Alliance, a non-profit organization
10 dedicated to improving the lives of individuals with
11 phenylketonuria.

○